



A Conversation with Rita M. Gardner about the Crisis in Adult Services

Conducted by Mary Jane Weiss, Ph.D., BCBA-D, March 2022



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President and CEO

Rita Gardner is President and CEO of Melmark, an organization that serves individuals with autism in Pennsylvania, Massachusetts, and North Carolina, and has been a progressive leader in behavior analytic intervention for autism for decades.

Rita Gardner received her Master of Public Health degree from Boston University's School of Public Health in the School of Medicine. Rita has devoted over 35 years in non-profit management in the field of community-based services for children and adults with the diagnosis of autism spectrum disorders, acquired brain injuries, neurological disorders, and severe challenging behaviors. She has been involved in the organization, design, development and implementation of over 100 community-based programs for children and adults. Her professional experience is focused on high-level organizational design using her skills in advocacy, clinical practice, health

service administration, legal issues, public policy and fundraising. She has shaped public policy, developed premier service provision organizations that serve as models of excellence, and has served as a tireless advocate for individuals with autism, for their families, and for the professionals who serve this population. I have prepared some questions to shed light on the crisis in adult services, not just in MA or PA or NC, but nationwide. This is a good opportunity for us all to pause and look at the barriers that exist for adult services for people with ASD. It is also instructive, as Rita outlines some urgent directions for advocacy and for service delivery improvements.

Mary Jane: What are some of the barriers that exist for adult services for individuals with autism spectrum disorder (ASD); what are the biggest barriers in vocational and residential support planning?

Rita: I think the state of access has changed due to the Covid-19 pandemic. Prior to the pandemic, I might have said the funding and access to quality providers was the number one issue. With the onset of the Covid-19 pandemic, I think the number one issue is the workforce crisis and access to direct support professionals. For individuals with autism, and especially those with significant behavioral support needs, the level of credentialed staff to help support effective interventions is severely lacking. If you look over the past few decades, that group of staff has become increasingly vulnerable to other issues (e.g., loss of jobs; changes in work locations and responsibilities), as the served population has aged. They moved into personal aide roles in nursing homes and other long-term care settings. We have difficulty even recruiting enough staff for our current programs. The ongoing Covid-19 pandemic crisis has made that worse. People do not want to work on the frontline. Furthermore, the federal reimbursement for most Medicaid waiver programs has been suppressed for decades. So, salaries across the United States are too low to sustain high quality services.

Mary Jane: What is the impact of adult service access challenges on family members?

Rita: For many families, the familial stress burden is increasing dramatically, there is very little respite opportunity throughout the pandemic for families. For those aging out of children's services, the transition process is fractured, if not broken. This fracture is causing inordinate stress for families as they try to navigate and access services for their young adult. The stressors of individuals with autism means they do not have optimal supports. They may be placed in temporary settings, which creates another transition for individuals who often already find transitions difficult and should be not experiencing additional barriers to receiving services.

Mary Jane: What is the availability of a competent workforce for adults with autism? What are the most urgent needs are for recruiting, training, retention?

Rita: The issue is around workforce. Most agencies were seeing between 10 to 15 percent vacancy rate prior to the pandemic. Now many agencies are reporting, 40, up to 50, or even 65 percent vacancies; many workers left the workforce during the pandemic. We need to get much more creative about how to bring people into our workforce, including starting literally at the high school (HS) level with internships in human services. And we need to be really looking at how we do onboarding and how we do performance training. It is imperative that we make sure it becomes a job with a livable wage. People can then move up a professional hierarchy. They could go from a HS diploma, to an associate's diploma, to a bachelor's, and to a master's degree. As an example, in Pennsylvania, there has been a significant comparison to what a state worker Direct Service Professional (DSP) makes in a state institution and what a non-profit DSP worker makes. It is four to five more dollars per hour, and that does not include benefits. There needs to be equal pay for equal work. You can't pay people less in the community when you provide so much more in the state institutions to state workers. We need to get creative in training and performance management systems. We want to help people become invested in the field, not just with young children with autism, but also as people age through the lifespan. And it is not just what we need to do within our organizations, but also on the state and federal levels.

Mary Jane: Can you describe the specific issues for those with more complex needs? Are the access issues more severe for them?

Rita: For those with more complex needs, the workforce crisis has impacted folks more severely due to the intensity of supports needed for their day-to-day services. For many Day programs, when evaluating whom to bring back to services post-pandemic closures, the number of staff needed for supports figures into whether or not an individual can return to Day services.

For example, when a Day program re-opens, if an individual requires 1:1 services, or there are three adults who only require one staff, we are seeing the individual with complex needs not returning to programs. This makes adults with complex ASD even more vulnerable as they then lose life-sustaining services. The workforce crisis has created inequity in the availability of services, and it has affected those who are impacted more severely by their disabilities most dramatically.

Mary Jane: SIAT is a publication read by parents and professionals alike. To reach those audiences, what can parents do to plan for adulthood and to advocate for services for their adult child? What can providers do to meet these needs, to plan for adulthood, to ensure that services are tailored to adult goals and challenges? Finally, what kind of advocacy might help solve this problem on a larger scale? How can these invisible needs be highlighted so that more services can be developed?

Rita: Parents should research service options in their home state well in advance of transition age. They should join advocacy groups for adult services and share their family's story with state and federal legislators. There are no more powerful voices than the adult and family speaking directly to their elected officials about their support needs.

There needs to be increasing pressure by families to demand funding commitments for services to the young adult transitioning to adulthood. Too often the families believe providers should be doing more – but until better funding streams are developed – the vast majority of providers having stopped expanding adult services for individuals in ASD due to funding and the workforce crisis. Unfortunately, when service providers advocate for additional funding, it is seen as self-serving. When additional funds are requested by families, it is seen as a need that must be met.

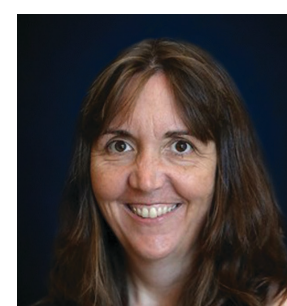
Mary Jane: Melmark is known for compassionate care and for a focus on quality of life. How are these commitments relevant for service provision to adults with special needs? How can parents identify programs that espouse these ideals and provide humane, effective treatment?

Rita: Melmark's core commitments try to focus on all the needs of an individual taking into account the developmental process as people are aging. We are always trying to be proactive with our planning around services and treatment needs- usually planning 5-7 years out.

These plans may include facility design, healthcare supports, anticipated changes in ambulation, sexual education training and support, recreation, working towards community living, vocational planning, financial training for our individuals, ongoing clinical services and supports, and collaborating with families around all these matters and more.

Parents have to ask a lot of questions about services, how providers plan and adapt to changing needs. In addition, they should ask about the use of evidence-based practice, and the extent to which decisions are informed by data. It is important to know that intervention is methodical and individualized.

There is no one perfect provider, and many providers have very limited resources. What you want to look for is direct communication, transparency in services (including challenges), and the ability to partner on advocacy to improve all outcomes.



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Mary Jane: You have outlined a large set of challenges for us all, but you have also signaled some important action items to help the field successfully meet these challenges. The need for a competent workforce is clear; staff need to be trained to deliver effective, high-quality services. Furthermore, services must be tailored to each individual, and there is an urgent need to ensure that the needs of those most impacted by autism are not overlooked. Finally, concomitant emphases on compassionate, humane care and on quality-of-life issues will help ensure that the field is working to deliver outcomes that matter for those we serve. Thank you for sharing your wisdom and expertise with the ASAT community, and for leading the way in envisioning and delivering exemplary services.

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